

ANNUAL REPORT 2021

Public Health Neonatal Abstinence Syndrome Reporting Registry, 2020 Births



Kentucky Department for Public Health
Division of Maternal and Child Health



KENTUCKY
CABINET FOR HEALTH
AND FAMILY SERVICES



Neonatal Abstinence Syndrome Reporting Registry – Annual Report 2021

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Executive Summary

The Kentucky Public Health Neonatal Abstinence Syndrome (NAS) Reporting Registry received fewer reports of Neonatal Abstinence Syndrome (NAS) in 2020 than in 2019. In 2020, there were 993 cases of babies with signs and symptoms of NAS; this accounts for 19.4 births for every 1,000 live births among Kentucky residents. Rates are highest in Appalachian areas of the state, in some areas reaching 77 cases per 1,000 live births. In comparison, the most recent national estimate for NAS was 7.3 cases per 1,000 live births (HCUP Fast Stats, 2020). Mothers of infants with NAS tend to have less education, be unmarried, and have more children, which may suggest lower socioeconomic status, a lack of social support, or reduced access to services.

The most frequent opioids reported were buprenorphine (64%), heroin (19%), and methadone (11%). Importantly, about 54% of the women in the registry were enrolled in Medication for Opioid Use Disorder (MOUD) treatment. Enrollment and retention in MOUD, specifically buprenorphine or methadone, is one factor associated with adequate prenatal care and healthy outcomes for the parent and baby.

Other commonly used substances are amphetamines, including methamphetamine (36%), and cannabinoids (28%). All other substances were used by less than 12% of women in the registry. Approximately 61% of cases were exposed to more than one type of substance during pregnancy; for these cases, the average exposure was to three substances.

Prenatal care is critical for these women to address illicit substance use and other co-occurring problems, such as hepatitis C, which was reported in about 38% of mothers of babies with NAS. Compared to women whose infants do not have NAS, mothers of infants with NAS are more likely to utilize Women, Infants, and Children (WIC) services during pregnancy, but much less likely to receive first trimester prenatal care. Inadequate health insurance may explain part of this disparity, as 6.35 of mothers in the registry did not have insurance of any type to pay for their delivery.

Infants with NAS are almost twice as likely to have a low birth weight and almost three times as likely to be admitted to a neonatal intensive care unit. Tobacco use co-occurs with substance use at high rates, which could further affect the health and development of these infants. Infants with NAS had longer delivery hospitalizations: 12.6 days as compared to 3.6 days for infants without NAS. Infants who received pharmacological treatment (46%) had average stays of 20.6 days. Among this group, the most common treatment was morphine (87%), followed by clonidine (28%); about 29% received multiple medications.

About 86% of infants with NAS were referred to the Kentucky Department for Community Based Services, and 43% of those cases were accepted for investigation. Data from other Kentucky programs indicates that NAS is a risk factor for fatal or near-fatal child abuse including abusive head trauma and Sudden Unexpected Infant Death.

In addressing NAS and the issues of families affected by substance use, the Kentucky Department for Public Health recommends: continuing to promote prenatal care; promoting enrollment in MOUD programs; implementing a plan of safe care including educating parents and medical/child care providers on safe sleep, abusive head trauma, child abuse and neglect; enrollment in services such as WIC and home visiting; and improving access to long-acting reversible contraception.

Background

The Opioid Epidemic

Opioid use disorder (OUD) is widespread and severe nationwide, but Appalachia may be the area that is hardest-hit. The region has some of the highest opioid prescription rates in the United States (U.S.) (CDC, “U.S. County Prescribing Rates,” 2017), and many rural Appalachians believe that drug addiction and misuse is the biggest problem in their communities (NPR, RWJF, Harvard, 2018).

Opioids are a class of narcotics that bind to receptors in the brain to produce pain relief, anesthesia, or euphoria (Hughes et al., 2016). After prolonged use, increasing doses are needed to produce an effect (tolerance), which can lead to drug overdoses (ACOG, “Opioid,” 2017); these overdoses may result in kidney failure, heart problems, nerve damage, anoxic brain injuries, and death (Clark, 2014).

Between 1999 and 2015, overdose fatalities quadrupled in the U.S. (O’Donnell, Gladden, & Seth, 2017), driven by synthetic opioids (O’Donnell, Halpin, Mattson, Goldberger, & Gladden, 2017; O’Donnell, Gladden, & Seth, 2017) or other illicit substances (O’Donnell, Gladden, Mattson, Hunter, & Davis, 2020). During the early months of the COVID-19 pandemic, reports of hospitalization, emergency medical services, and deaths due to opioid overdoses increased greatly in various areas of the U.S., including Kentucky (Rodda, West, & LeSaint, 2020; Slavova, Rock, Bush, Quesinberry, & Walsh, 2020).

Surveys by Foundation for a Healthy Kentucky found that two out of every three Kentuckians know someone who has experienced problems as a result of drug use, and more than twice as many people knew someone who used heroin in 2018 than in 2013 (2019). Reported methamphetamine use also increased during this time.

2 out of 5

rural Appalachians believe that drug addiction and misuse is the biggest problem facing their community.



2 out of 3

Kentuckians know someone who has experienced problems as a result of drug use.

Impact on Maternal and Child Health

Infants with prenatal substance exposure, including opioid exposure, may experience effects upon its discontinuation, also known as Neonatal Abstinence Syndrome (NAS) (Kocherlakota, 2014). Many over the counter or prescription medications can cause NAS (Hudak & Tan, 2012), so the diagnosis does not inherently indicate illicit activity by the mother. NAS presents similarly to withdrawal in adults, including restlessness, tremors, seizure, vomiting, fever, sweating, and apnea (Hudak & Tan, 2012), although symptoms may vary in presentation, duration, and severity. Because symptoms are non-specific, toxicology screenings and maternal history are important in establishing in utero exposure. NAS can be treated by comfort care such as swaddling, rocking, and reducing environmental stimuli (Kocherlakota, 2014), but pharmacological intervention is sometimes used in severe cases (MacMillan, 2019). Treatment may take place in a Neonatal Intensive Care Unit (NICU) or other special care unit (MacMillan, 2019).

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Between 1999 and 2014 in Kentucky, the rate of opioid use disorder (OUD) increased 48-fold to 19 cases per every 1,000 deliveries (Haight, Ko, Tong, Bohm, & Callaghan, 2018). However, women with OUD make up only a fraction of the estimated one in fifteen who take opioids during pregnancy (Ko et al., 2020).

Methodology and Limitations

In 2013, the Kentucky General Assembly enacted Kentucky Revised Statute (KRS) 211.676, establishing NAS as a reportable disease. Mandatory statewide reporting to the Public Health NAS Reporting Registry (from here on, “the NAS Registry”) began on July 15, 2014. The NAS Registry collects information from Kentucky hospitals on Kentucky resident children with NAS and a history of prenatal substance exposure. Case reporting is not tied to the International Classification of Disease (ICD-9 or ICD-10) codes.

KRS 211.678 outlines the confidentiality requirements of the NAS Registry and calls for an annual report of aggregated data. This annual report includes the calendar year 2020 births. Cases were linked to the Certificate of Live Birth to obtain additional information and to provide a comparison group. Cases were excluded if they did not meet all criteria: Kentucky resident, born in 2020, with NAS symptoms. Duplicate cases were also excluded.

Unless otherwise stated, all figures and tables show preliminary unduplicated case counts of Kentucky residents for the birth year 2020 from the NAS Registry and the Office of Vital Statistics. Any category with less than five (<5) cases is suppressed, and categories with 5-19 cases should be interpreted with caution as rare outcomes may lead to unstable estimates. Results may be presented as rates of NAS per 1,000 live births, calculated as follows:

$$\frac{\text{Number of cases} \times 1,000}{\text{Total number of live births}}$$

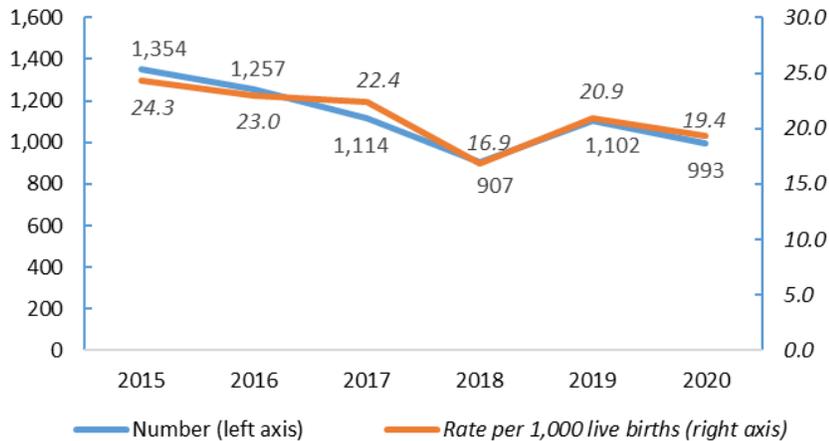
The NAS Registry is a passive surveillance system, and as such is limited by the reporting practices of different hospitals or individual hospital employees. Overall, 35 hospitals reported 2020 cases to the NAS Registry. Delayed reporting can negatively affect data quality. For 2020 cases, the average submission time is 69 days after discharge, which is more than twice the 30 day goal. The data system does not differentiate the details of timing and intent of substance use, which affects data on polysubstance use and Medication for Opioid Use Disorder (MOUD). Finally, Kentucky resident births that occur at facilities outside of Kentucky and are not transferred to a Kentucky hospital are not reported to the NAS Registry, which could result in underreporting near state borders.

Data and Results

Kentucky Incidence

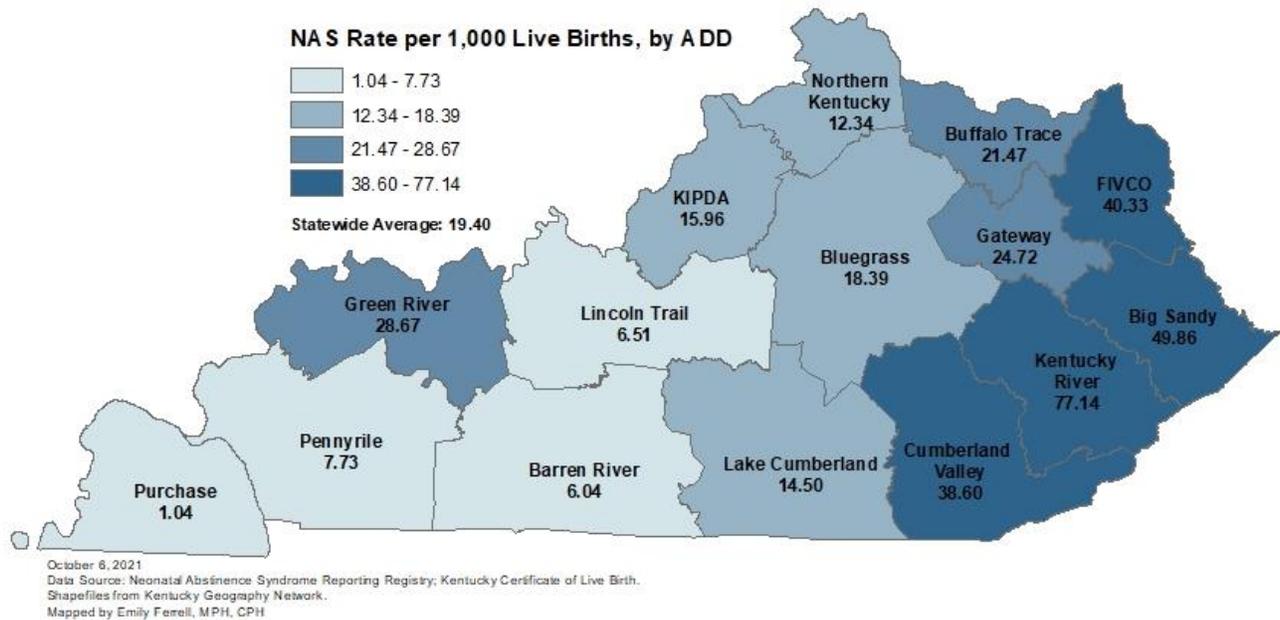
Kentucky’s NAS rate remains far above the national average. Data from the NAS Registry shows 993 unduplicated cases in 2020, which is a decrease from 2019 (Figure 1).

Figure 1. Kentucky Resident NAS Cases, 2015-2019



There are large discrepancies within Area Development Districts (ADDs) across Kentucky with rates ranging from 1.0 to 77.1 cases per 1,000 live births (Figure 2). In Kentucky, the rate of NAS in rural counties is nearly twice the rate in urban counties, with the highest rates in Appalachia.

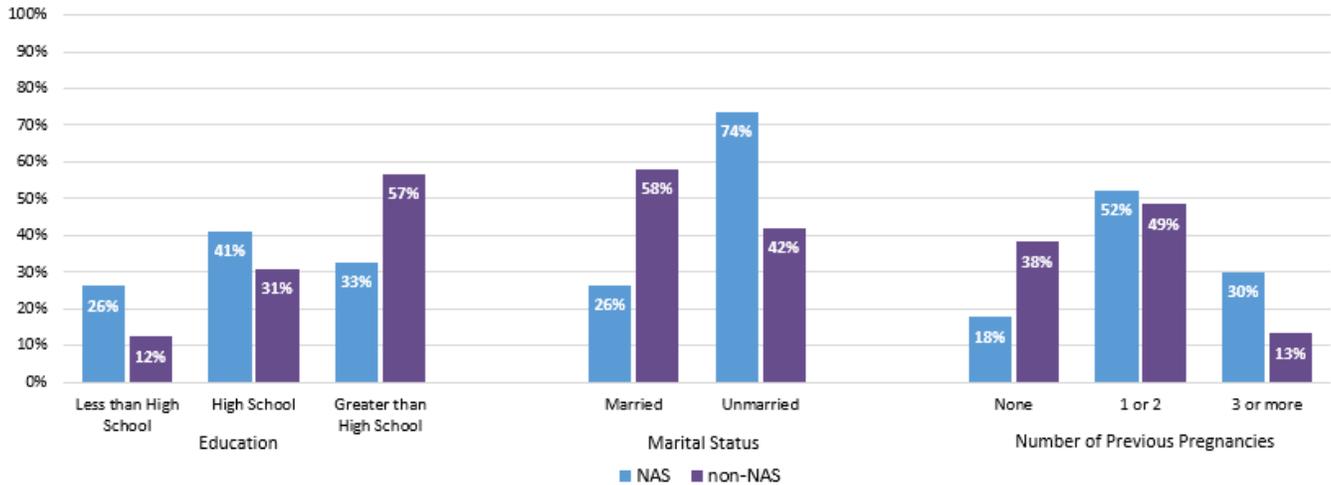
Figure 2. NAS Rate By ADD of Residence, 2020



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Mothers of infants with NAS (compared to mothers of infants without NAS) tended to have less education, be unmarried, and have more children (Figure 3). Those factors may indicate lower socioeconomic status, less social support, lack of access to family planning services, or limited health literacy. Identifying demographic patterns and addressing social determinants of health are important steps in developing interventions to reach high-risk populations.

Figure 3. Education, Marital Status, and Pregnancies of Mothers by NAS Status of Child, 2020



Frequent Substances Used

Table 1 includes all substances included in the NAS Registry (excluding tobacco and alcohol) by category, ranked from most to least commonly reported. This table takes into account any indication of exposure (maternal history, maternal toxicology screen positive, and/or infant toxicology screen positive). From year to year, there have been no major changes in the rankings of substances.

Table 1. Frequency of All Substance Groups in the Public Health NAS Reporting Registry, 2020

Frequency of Opioids in the Public Health NAS Reporting Registry		Frequency of Other Substances in the Public Health NAS Reporting Registry	
<i>Any of the below opioids</i>	85.80%	(Meth)Amphetamines	35.55%
Buprenorphine	64.25%	Cannabinoid	28.30%
Heroin	18.93%	Benzodiazepines	11.08%
Methadone	10.53%	Gabapentin	6.34%
Fentanyl	9.67%	Cocaine	5.94%
Oxycodone	6.45%	SSRIs	1.61%
Hydrocodone	3.83%	Barbiturates	0.91%
Tramadol	1.41%	Tricyclics	0.60%
Unspecified Opioids	33.03%		

Note: Numbers will not add to 100% as more than one substance can be reported per case and not all substances are shown in the table above. The category (Meth)Amphetamines includes any indication of use of methamphetamine and/or amphetamines.

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The most common substance in the NAS Registry is buprenorphine, a partial opioid agonist with low potential for misuse which is used to reduce withdrawal and cravings (SAMHSA, 2016). While it can be associated with NAS, its use as part of supervised MOUD is preferable to untreated OUD during pregnancy. Increased access to MOUD may explain why buprenorphine is one of the most common substances in the NAS Registry. The second most common reported substance was “all other opioids,” which were reported about one out of every three cases. Non-specific toxicology reports or maternal histories of opioid use make up the majority of this category.

More than one-quarter of the cases in the NAS Registry were exposed to cannabinoids. Cannabis is the most commonly used illicit drug in the U.S., with about 7%-15% of pregnant women likely using it (McCance-Katz, 2018; Garg et al., 2016). Women who use cannabis during pregnancy believe there are few adverse effects compared to the perceived therapeutic value (Weisbeck et al., 2020). The American College of Obstetricians and Gynecologists (ACOG) discourages marijuana use during pregnancy due to a lack of studies on its safety (ACOG, “Marijuana,” 2017). Although cannabis is not known to cause NAS, it is associated with pregnant women using other substances, including tobacco, alcohol, and opioids (Passey, Sanson-Fisher, D’Este, & Stirling, 2014).

The use of fentanyl and amphetamines including methamphetamine have been increasing in recent years. Fentanyl more than doubled from 2018 to 2020 (3.86% to 9.67%) and (meth)amphetamines increased from 23.07% in 2017 to 35.55% in 2020.

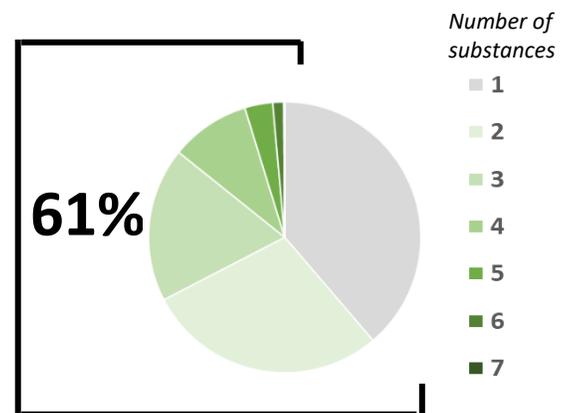
About 61% of cases had polysubstance use, which in this report means the use of substances from more than one type or category (see Table 1), excluding tobacco and alcohol. About 29% of women used two types of substances, and about 32% used three or more types of substances; on average, cases with polysubstance use had exposures to three types of substances. Polysubstance use may contribute to prolonged or more severe NAS symptoms. Substances such as cocaine, benzodiazepines (Hudak & Tan, 2012), and antidepressants (Kaltenbach et al., 2012) can be associated with worsened NAS symptoms when combined with opiates.

Over half (54.3%) of the women had a prescription for medications to treat addiction, indicating enrollment in MOUD. Prescriptions for pain treatment and psychiatric treatment were much less common (<6% of women for each), which aligns with the low reported frequencies of those medications.

Prenatal Care

The prenatal period presents a unique window of opportunity for women to make many changes in their health and lifestyle, including management of OUD (ACOG, “Opioid,” 2017). Just over half of the mothers in the NAS Registry received at least adequate prenatal care (using the Kotelchuck index), compared to three out of four mothers who did not have infants with NAS.

Figure 4. Frequency of Polysubstance Use



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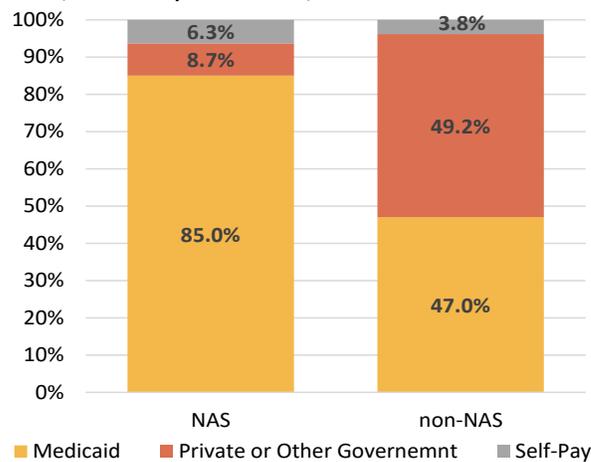
As part of prenatal care, ACOG recommends women with OUD are screened for infections including hepatitis C (ACOG, “Opioid,” 2017). The hepatitis C rate among mothers whose children did not have NAS was 1.9%, compared to 38.3% among those whose children had NAS. These concerns led to the passage of Senate Bill 250 in April 2018, which added universal screening of pregnant women for hepatitis C to KRS 214.160.

Hepatitis C is 20x more common in mothers of infants with NAS.

Over half of the mothers whose infants had NAS received services through the Women, Infants, and Children program (WIC) during pregnancy. Enrollment in WIC can ensure proper nutrition for an infant who is at risk of feeding difficulties, provide assistance with breastfeeding, and refer mothers to additional services.

Disparities in insurance coverage, shown in Figure 5, give one possible explanation for disparities in prenatal care utilization. Deliveries of infants with NAS were more likely to be paid out of pocket as opposed to deliveries of infants without NAS (6.3% versus 3.8%), and these mothers may lack insurance to cover prenatal care. With three-quarters of babies with NAS having Medicaid, as opposed to about half of the non-NAS population, Medicaid organizations have the ability to reach this population and work with them to promote prenatal, postpartum, and pediatric care. By ensuring appropriate preventive services, it may be possible to avoid costly outcomes in the future.

Figure 5. Insurance Type at Time of Delivery, by NAS Status, Kentucky Residents, 2020



Another factor in prenatal care utilization is enrollment in and retention with MOUD. MOUD includes the medications buprenorphine and methadone and is provided as part of a treatment plan along with objective behavioral modification. There is insufficient information about the safety of extended-release naltrexone during pregnancy. Enrollment in prenatal care, MOUD, and counseling provides additional benefits to mothers. The rate of MOUD enrollment (51%) is slightly lower than last year. In this report, MOUD means having a valid prescription for the treatment of an opioid use disorder.

Newborn Outcomes

In the wake of the opioid epidemic, alcohol and tobacco are often overlooked although both forms of prenatal substance exposure can have negative effects such as developmental delays and preterm birth (Bishop et al., 2017) and can cause withdrawal-like symptoms in infants (Hudak & Tan, 2012). Kentucky Office of Vital Statistics data show that 14% of women whose babies did not have NAS reported smoking during pregnancy, which increases to 68% for women whose babies have NAS. Data collected in the NAS Registry is even higher with 79% of women reporting tobacco use.



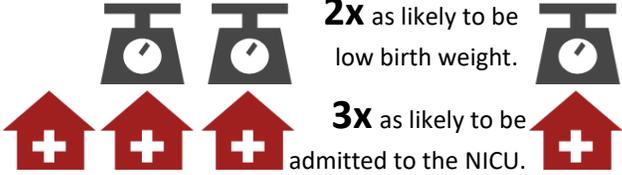
4 out of 5 babies with NAS had mothers who smoked during pregnancy.

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The prevalence of alcohol use during pregnancy is not well known, as it is vastly underreported but is estimated to be approximately 10% (CDC, 2015). Alcohol use was reported by mothers of 4.8% of infants with NAS in Kentucky, which may be lower than the actual rate of use.

Compared to infants without NAS, infants with NAS are nearly twice as likely to be low birth weight (LBW) defined as less than 2,500 grams. Underlying social, behavioral, and biomedical factors (Schempf & Strobino, 2008) may be partly responsible for this finding. Infants with NAS can have difficulties feeding and gaining weight (Hudak & Tan, 2012), which further increases the health risks and challenges associated with preterm and LBW.

Babies with NAS are



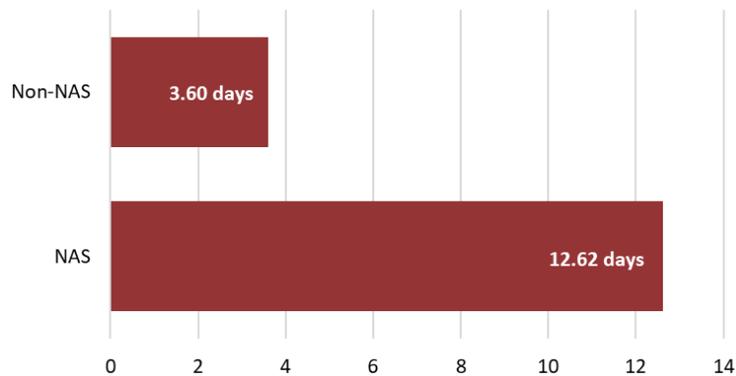
2x as likely to be low birth weight.

3x as likely to be admitted to the NICU.

Compared to babies who do not have NAS.

These conditions are associated with medical complications that result in longer duration of hospitalization. In 2020, about one in ten newborns without NAS had NICU stays, compared to nearly three in every ten newborns with NAS, and there is a national trend of NICUs dedicating increasing resources to NAS (Tolia et al., 2015). Infants with NAS also have a much longer length of stay (LOS): 12.62 days versus 3.60 days.

Figure 6. Length of Stay by NAS Status, 2020



As symptoms do not develop immediately (Kocherlakota, 2014), the American Academy of Pediatrics (AAP) (Hudak & Tan, 2012), and the World Health Organization (2014) both recommend observing infants with NAS in the hospital for four to seven days post-delivery. In 2020, the average age at onset of symptoms was 29.2 hours; 16% of cases in the registry did not develop symptoms until at least 48 hours after birth.

One factor contributing to the length of stay is pharmacological treatment for NAS; infants receiving medication for NAS have a longer LOS than those who receive comfort care only (20.6 days compared to 5.9 days). Overall, 46% of infants with NAS received one or more medications to treat NAS.

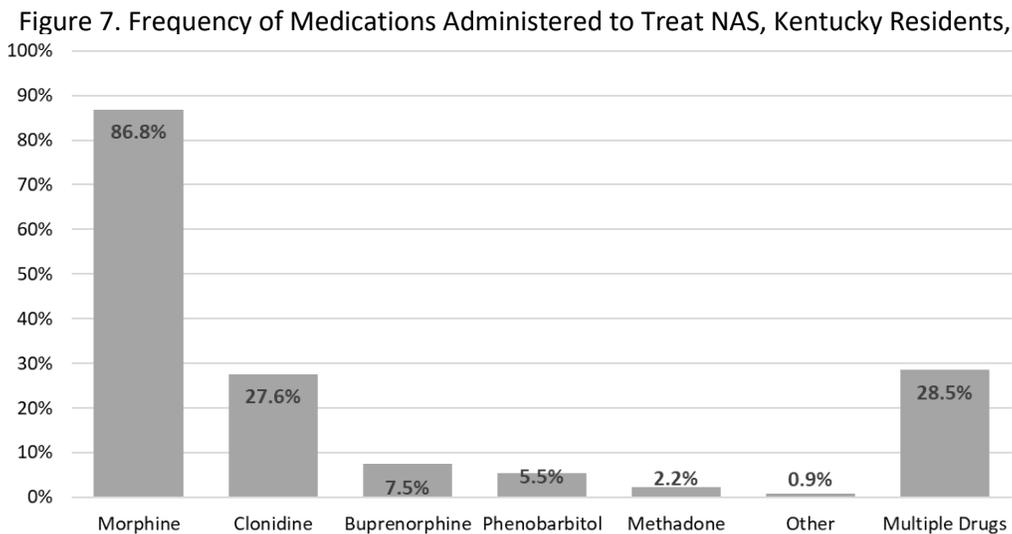


Nearly **1 out of every 2** infants with NAS was treated with medication.

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Nearly nine out of every ten treated infants received morphine, which is consistent with research on prescribing practices (Hudak & Tan, 2012). Clonidine was used in over one-quarter of treated cases, although there are few studies on its use to alleviate NAS symptoms in infants (Hudak & Tan, 2012). All other medications were administered to <10% of infants who received medication. Over one-quarter of infants who received treatment were prescribed more than one medication.

When considering pharmacological treatments for NAS, the first concern is that treatment should be both safe and effective. NAS may cause distress or discomfort but it is ultimately self-limiting, and unnecessary medication may prolong or exacerbate the process (Hudak & Tan, 2012).



Some interventions that help reduce the severity of NAS can be provided instead of or in addition to pharmacological treatment. Breastfeeding may reduce the severity of NAS symptoms (Hudak & Tan 2012; ACOG, “Opioid,” 2017). From birth certificate data, mothers of infants with NAS are much less likely to plan to breastfeed as mothers of infants without NAS (39% vs 73%, respectively); according to the NAS Registry, only about 22% initiate breastfeeding.



ACOG **recommends breastfeeding**, unless contraindicated.

Outcomes Beyond Discharge

In addition to the lack of insurance, women with OUD might have less interaction with the healthcare system because they fear civil or criminal charges or reporting to child welfare agencies. These fears are not baseless, as many states define substance use during pregnancy as child abuse (Guttmacher Institute, 2019). As part of the Child Abuse Prevention and Treatment Act (CAPTA), states must have policies to notify child welfare agencies about infants with prenatal substance exposure. Nationwide, in fiscal year 2019, over 86,000 children entering foster care had parental drug misuse as a circumstance of removal from the home (Children’s Bureau, 2020). Of

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the infants in the 2020 cohort of the NAS Registry, 7 out of every 10 are discharged to the care of one or both biological parents and 1 out of every 4 are discharged to kinship care, foster care, or an adoptive parent.

As stated in the Kentucky Cabinet for Health and Family Services (CHFS) standard of practice manual, reports may be accepted alleging risk of harm if a “caretaker engages in a pattern of conduct that renders him/her incapable of caring for the immediate and ongoing needs of the child” due to substance misuse (2020). That policy includes the example of infants testing positive or experiencing withdrawal from non-prescribed substances. For that reason, medical providers are expected to document prenatal substance exposure in the medical record. Of all infants in the NAS Registry, 86% were referred to DCBS; 43% of those were accepted. The referral rate is very similar to what was reported last year, indicating consistency of practice. The acceptance rate decreased from last year’s 76%, which could be due to hospital data submission practices, rather than changes in DCBS practice.

The Child Fatality and Near Fatality External Review Panel (“the Panel”) conducts comprehensive, multidisciplinary reviews to discover risk factors and systems issues and recommend prevention measures (2019). Historically, a large proportion of cases, especially abusive head trauma cases, have had caregiver substance misuse as a risk factor. Recommendations from the Panel have been incorporated into this report.

Data from Kentucky’s Sudden Unexpected Infant Death (SUID) Case Registry shows that in 2016-2019, 32% of cases had a risk factor related to substance use (including NAS and parental/caregiver use). This data could indicate that NAS is a risk factor for SUID, but there is not a known biological mechanism for that relationship. Caregiving or co-sleeping while impaired could also endanger infants.

Concluding Statement

NAS is just one facet of the opioid epidemic and cannot be addressed in isolation from larger systemic issues. Although the problem is daunting, prevention is possible. The following recommendations help address the underlying determinants of health to promote better outcomes for families and children.

Recommendations for Prevention

Promote optimal well-woman health, periconceptional health, prenatal care, and postpartum care. Optimal health and periconceptional status promotes healthy pregnancy. Prenatal care and postpartum care ensure monitoring for any medical or fetal complication and screening for substance use disorder and co-morbidities so that referral can be made for treatment and counseling.

Referral and enrollment in MOUD programs. In the NAS Registry over half of the women report having a prescription for MOUD. MOUD programs, especially those that incorporate comprehensive services to address the complex needs of the mother and family, can be very successful in addressing OUD. To support recovery, MOUD should be more accessible for both pregnant and postpartum women. Resources such as findhelpnowky.org can be used to locate a variety of treatment options. For more information on evidence-based treatment, see the Substance Abuse and Mental Health Administration’s Clinical Guidance for Treating Pregnant and Parenting Women with Opioid Use Disorder and their Infants. Furthermore, MOUD providers would benefit from training and engagement in family-oriented protocols as well as collaborative and holistic services directed to pregnant women, or mothers and their infants.

Implement a plan of safe care. Every infant, including those prenatally exposed to drugs or alcohol, should leave the hospital with an appropriate plan of safe care. A plan of safe care should address coordinated and integrated services needed for the impacted child, parent(s), and caregivers. The Kentucky Department for Public Health (KDPH) has the community outreach structure in place to help bridge the widening gap between the need for and availability of services or resources. Interagency collaboration among the Department for Behavioral Health, Developmental and Intellectual Disabilities, Department of Community-Based Services, and KDPH will assure that plans of safe care are implemented for infants with NAS or any substance exposure.

Education for parents on abusive head trauma and safe sleep. Birthing hospitals provide in-person, evidence-informed education regarding safe sleep and abusive head trauma prevention to parents as part of antepartum, intrapartum, and postpartum care. Continuing this as universal practice will ensure that all parents of infants with NAS or prenatal substance exposure are reached. To that end, the Kentucky Hospital Association supports this practice. The KDPH continues to promote the **ABCD** of safe sleep practice (Babies sleep **A**lone, on their **B**ack, in a **C**rib, and attended to without **D**anger from a caretaker who is impaired, tired, or distracted).

Implement the practice of modeling safe sleep among healthcare and childcare providers. Infants with NAS have an increased risk of Sudden Unexpected Infant Death (SUID), which may be reduced through safe sleep practices. Healthcare and childcare providers are uniquely positioned to encourage these practices through modeling and should do so universally.

Increase enrollment in services such as WIC and home visiting. Programs that serve mothers and families prenatally and throughout early childhood have unique opportunities for engagement. These programs should incorporate substance misuse education into curricula on healthy pregnancies, in addition to making referrals to counseling or treatment, community resources, and monitor the parent’s and child’s well-being. For more information about home visiting in Kentucky, families can visit <http://www.kyhands.com/>

Increase collaboration among programs that address and prevent OUD and maternal morbidities and mortality. Programs such as the Kentucky Perinatal Quality Collaborative (KyPQC), the KY Alliance for Innovation on Maternal Health (AIM), the Maternal Mortality Review Committee (MMRC), and the NAS Public Health

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Reporting Registry should work together to collect and share data, to implement prevention activities, and to evaluate outcomes.

Improve access to long-acting reversible contraception (LARC). Only 18% of infants with NAS were the first live birth to that mother, compared to 42% of infants without NAS. This demographic trend has been consistent across the past few years, with the additional context that nearly 90% of pregnancies among this population are unintended (Heil et al., 2010). Women of reproductive age who use opioids for any purpose need effective pre-conception counseling and access to family planning. Kentucky Medicaid covers LARCs, and other insurers and providers should work to make LARCs accessible to all interested mothers during the intrapartum period. Efforts to facilitate administration of injectable contraceptives at syringe service programs could also be effective for women of reproductive age with OUD.

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